Don't Take Liberties with Our Genes

By Philip Bereano

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The Human Genome Project at the National Institutes of Health, according to President Clinton, "will one day in the not-too-distant future enable every set of parents that has a little baby to get a map of the genetic structure of their child. So if their child has a predisposition to a certain kind of illness or a certain kind of problem, . . . they will be able to plan that child's life, that child's upbringing, to minimize the possibility of the child developing that illness or that predisposition (in order to) enable untold numbers of people to have far more full lives than would have been the case before . . . ."[1]

President Clinton's picture of a wonderful technofuture sounds like a threatening Brave New World to many Americans. The confluence of several technical and social trends has greatly enhanced the capacity for genetic surveillance and tracking:

- The science of genetics is a flourishing new industry, nourished in large part by the federally funded Human Genome Project, which recently claimed the almost complete sequencing of the genome's 3.2 billion sub-units of DNA. The ultimate goal of this ambitious research endeavor is to identify every gene found in the human body, an unknown number with estimates ranging from about 35,000 to more than 100,000. Spinoff research at biotech companies and universities focuses on genetic diagnostics, developing tests to identify genes thought to be associated with various medical conditions. Scores of new genetic tests have evolved in the past five years alone.
- The increasing speed, sophistication, affordability, and interconnectivity of computer systems allows the rapid monitoring and matching of many millions of genetic records.
- The promotion of an "ideology of geneticization" fosters the belief that genes are determinants of a person's behavior, character, and future. In the words of Nobel Laureate James Watson, "We used to believe our destiny was in the stars; now we know it is in our genes." (The critical role of environment, and the complex interplay between a genome and its surroundings, are largely ignored in the media and public discourse about genetics.)
- Capitalist economic relations have created a mad scramble for venture capital and have intensified pressures to alter patent laws. Many researchers are calling for mass genetic testing.

Values Underlying Genetic Research

The dominant ideology in Western society proclaims that science and technology are value-neutral, and the only problems caused by technologies are either "externalities" (unintended side effects) or abuses. However, technologies are *not* value-neutral; they usually embody the perspectives, purposes, and political objectives of powerful social groups.

Technologies are the result of human interventions into the otherwise natural progression of activities, and are thus imbued with intentions and purposes. Current technologies do not equally benefit all segments of society — and indeed are not intended to do so.

In the United States, social and economic forces are exacerbating the differential access to wealth and power. Because technologies are intentional interventions into the environment, those with more power can determine which technological developments are researched and implemented. Thus, technologies themselves are not neutral; they are social and political

phenomena. Genetic technologies and computerization exhibit these characteristics and reflect power differentials in our society.

Genetic Tests, Class, Consent, and Privacy

The growing mania for testing in the United States is a manifestation of class relationships through new technological possibilities: employers test employees, insurance companies and health organizations test patients, college officials test students, legislators pass bills to test a variety of disempowered groups (welfare recipients, prisoners, immigrants, and the like). The consequences can be devastating::

• The U.S. Department of Defense insists on taking DNA samples from all its personnel, ostensibly for identification of those killed in action or in military accidents. Yet, the department will keep the samples for 50 years, long after personnel have left active duty. The testing also includes civilian employees, and the agency refuses to issue regulations barring all third-party use.

• The FBI has been promoting the genetic screening of criminals to establish state DNA identification data banks to be used in criminal investigations; recent federal legislation penalizes states fiscally if they don't participate. Screening also encompasses those whose crimes have low recidivism rates or don't leave tissue samples; some states even screen those who are merely accused of a crime.

The American Civil Liberties Union (ACLU) advocates that "the decision to undergo genetic screening is purely personal"; it should not be "subject to control or compulsion by third parties" or the government. The ACLU also maintains that a person who has agreed to genetic screening must be informed of the results, which should not be disclosed to third parties without the person's express and informed consent.

The required informed consent should define future allowable uses of the genetic samples so as to deny all future research uses for which such consent is lacking. If some argue that this restriction may compromise the ability to do research, we should remember that upholding civil liberties values often leads to inefficiencies; we could catch more crooks if we did away with the Fourth Amendment prohibition on warrantless searches.

Yet patients' records "are commodities for sale," in the words of *The New York Times*;[2] and a panel of the U.S. National Research Council has warned that the computerized medical records of millions of citizens are open to misuse and abuse.[3]

Authoritarian-minded public officials are trying to extend testing without consent. Louisiana has a statute requiring testing of all persons who are arrested (a provision a recent New York City police chief believed is worth enacting up north; New York City Mayor Rudolf Giuliani thinks everybody should be DNA-tested at birth).

Insurance and Genetic Discrimination

Genetic discrimination is the other major civil liberty issue. Scientists working with the Council for Responsible Genetics (CRG) have documented hundreds of cases where people have been denied insurance or employment based on genetic "predictions," for example:

• A healthy woman who casually mentioned to her doctor that her father had been diagnosed with Huntington's disease, and that she herself was at risk for inheriting this genetic disorder, was later denied disability insurance because insurers found a note about her father's diagnosis.

• A healthy boy who carried a gene pre-disposing him to a heart disorder was denied health coverage by his parents' insurance company, even though the boy took medication that eliminated his risk of heart disease.

• A pregnant woman whose fetus tested positive for cystic fibrosis was told by her health maintenance organization (HMO) that it would be willing to cover the cost of an abortion but would not cover the infant under the family's medical policy if she elected to carry the pregnancy to term.

Of course, relatively few genetic diseases are deterministic. Most tests (which have inherent limits) cannot tell us if a genetic mutation will become manifest; or if it does so, when in life this will occur or how severe the condition will be. In addition, many genetic conditions can be controlled or treated by interventions and environmental changes; that is why governments mandate testing newborns for PKU (phenylketonuria, a recessive hereditary metabolic disease that, if not treated from birth, may cause severe mental retardation).

Federal legislation, the Health Insurance Portability and Accountability Act (1996), limits genetic discrimination regarding certain medical insurance policies, but does not apply to others, nor to life, disability, or automobile insurance, nor to employment — all areas of documented discrimination. Slowly, state by state, the CRG, ACLU, and patients' rights groups are trying to get legislation passed to reduce or eliminate genetic discrimination; about 40 states have enacted some type of protection.

President Clinton announced his support of a federal bill to prohibit health insurance providers from using any type of genetic information for making decisions about whether to cover a person or what premium to charge. This legislation would address some of the recent discrimination problems.

Beyond the risk of discrimination, however, society's fascination with genetic determinism has other social and political consequences. Overemphasis on the roles of genes in human health neglects environmental and social factors. For example, strong evidence points to links between environmental contamination and cancer. Current research priorities, however, are skewed toward identifying genetic predispositions to cancer. If cancer is cast primarily as a genetic disease, then legislators may discard efforts to clean up environmental carcinogens in favor of a search for "cancer genes."

In effect, we encourage a "blame the victim" mindset that condemns people with "faulty" genes. Social conditions such as poverty or environmental pollution, which correlate directly with poor health and higher mortality rates, become less important. And economic and social resources are diverted into finding biomedical "solutions" while societal measures are short-changed.

Although new technologies claim to offer us more "freedom," they can threaten our civic values. This is certainly true of the new biology. As Jefferson warned, "the price of liberty is eternal vigilance" — it isn't genetically hard-wired to happen automatically.

Recommended Reading & Information Sources

Council for Responsible Genetics, http://www.gene-watch.org

Billings P (ed): *DNA on Trial*. Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press, 1992.

Hubbard R, Wald E: *Exploding the Gene Myth*. Boston: Beacon, 1993.

Kimball A: *The Human Body Shop: The Engineering and Marketing of Life*. San Francisco: Harper, 1993.

Lewontin R: *Biology as Ideology: The Doctrine of DNA*. New York, Harper Perennial, 1993.

Author

Philip L. Bereano, J.D., is a professor in the Department of Technical Communication at the UW College of Engineering, and adjunct professor in the Department of Women Studies and American Ethnic Studies in the College of Arts and Sciences. He is a founding board member of the Council for Responsible Genetics and is on the national board of the American Civil Liberties Union.